

## Reps. Castle & Baird Spearhead effort to Enhance Research of Pulmonary Fibrosis -- July 23, 2008

Research and Early  
Diagnosis Can Save Lives

Washington,  
D.C. - Today,  
very little is known about Pulmonary Fibrosis (PF), a debilitating lung disease that takes the lives of 40,000 Americans every year and kills an estimated two-thirds of patients within their first five years of diagnosis. The families of Representatives Mike Castle (R-DE) and Brian Baird (D-WA) have been personally impacted by PF and the two Congressmen have joined together to introduce the Pulmonary Fibrosis Research Enhancement Act, which will fund the creation of a national PF patient registry, and call on the National Institutes of Health (NIH) to expand and intensify PF research efforts on this disease that 128,000 Americans currently suffer from. This legislation builds on H.Con.Res. 182, which was the first-ever a Congressional recognition of the need for increased research funding and improved public awareness of PF in the United States.

"Pulmonary Fibrosis touches as many families annually as breast cancer, yet public awareness and medical research lag far behind," said Rep. Castle.

"PF is an ultimately debilitating and fatal disease, and one that has taken people close to me. By accelerating research efforts and creating a registry system to identify the cause and progression of the disease, we can find new and better approaches to treat and ultimately cure PF."

"We as Americans have shot the moon, spliced the gene, and split the atom," said Congressman Baird. "Together we can find the cause of, and cure for this dreaded disease. It only takes 3 things: creativity, courage, and cash."

Reps.  
Castle and Baird have been working closely with the Coalition for Pulmonary Fibrosis (CPF) to create a bill that will be the first of its kind to improve research and awareness of this deadly disease with no known cause, cure, or even treatment.

"The CPF is supportive of efforts that advance research to help the patients we serve," said Mishka Michon, Chief Executive Officer of the CPF. "We're delighted to have collaborated with these Members of Congress, and we are particularly grateful to Congressman Castle and Congressman Baird for their leadership on this first of its kind legislation to help pulmonary fibrosis patients."

Reps. Castle and Baird were joined by Reps. Nathan Deal (GA-09), Jim Gerlach (PA-6), Mark Kirk (IL-10), Marcy Kaptur (OH-9) Steve LaTourette (OH-14), Bill Young (FL-10), Jane Harman (CA-37) and Jackie Speier (CA-12) to introduce this bill.

According to the CPF, as many as 120 thousand people in the United States could be living with PF and not even know it. Research has shown the disease is more prevalent in men than in women, and most often occurs in people between the ages of 50 and 70. Life expectancy after diagnosis is usually less than 4 years.

Specifically, the Pulmonary Fibrosis Research Enhancement Act will:

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  - Encourage expanded federal research on PF at the National Institutes of Health (NIH) -
  
- o The Pulmonary Fibrosis Research Enhancement Act will encourage NIH to intensify and coordinate activities to understand, treat, and cure PF, with particular emphasis on genetic and environmental research, animal model research, and clinical research and trials.
  
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  - Create the first National PF Registry -
  
- o The national registry will improve data collection and information sharing in order to move the research forward more quickly. This effort will be lead by an advisory board comprised of government agencies, volunteer health organizations, patients and their advocates, and clinical experts and scientists. The Registry will expand upon existing data and will be made available to the NIH and the Department of Veterans Affairs.
  
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  - Create a National PF Action Plan -

o The Pulmonary Fibrosis Research Enhancement Act will direct the Centers for Disease Control (CDC) to work with the Advisory Board to prepare a comprehensive Action Plan for pursuing a cure for PF and addressing the costs and burden of pulmonary fibrosis.

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Call for a  
National Summit on PF -

o The Pulmonary Fibrosis Research Enhancement Act will call for a summit of researchers, representatives of academic institutions, federal and state policymakers, public health professionals, and representatives of national voluntary health organizations to be convened one year after enactment of the bill and every 3 years thereafter in an effort to provide greater coordination on PF research and prevention.

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